

Louisiana Developmental Disabilities Council
Position on Community Living for Individuals with Disabilities
Adopted April 2005, Updated October 21, 2010

Position Statement

Living in the community of their choice is a right most Americans take for granted; however, for those with disabilities in Louisiana this right cannot always be fully enjoyed or exercised. That is because Louisiana's system of services and supports for people with disabilities is overly reliant on institutional services that restrict people's ability to live where and how they choose. The Developmental Disabilities Council believes that

“Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens.” (Act 378 of the 1989 Louisiana Legislative Session).

Furthermore, public policy in Louisiana should encourage, accommodate and otherwise guarantee the free exercise of community living opportunities for all people with disabilities.

Discussion

It is clear that state and federal law recognize the value and necessity of community living for people with disabilities. The Developmental Disabilities Council fully supports the right of individuals with disabilities to live in the communities of their choice, and to enjoy equality of opportunity, full participation and independent living. Communities are enriched by full and active participation in community activities and contributions by individuals with developmental disabilities and their families. Evidence of positive outcomes and improved quality of life for people with disabilities who live in the community is overwhelming. Community living affords greater opportunities for full participation in the social and economic life of our communities and yields demonstrably greater benefits for individuals with disabilities than institutional care.¹ People living in community-based residences have more people in their social networks than do people living in developmental centers.²

“The goals of the Nation properly include a goal of providing individuals with developmental disabilities with the information, skills, opportunities, and support to make informed choices and decisions about their lives; pursue meaningful and productive lives; contribute to their families, communities, and States, and the Nation; have interdependent friendships and relationships with other persons and achieve full integration and inclusion in society, in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of each individual.” The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (P.L.106-402)

“The Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the

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United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity.” The Americans with Disabilities Act of 1990 (P.L.101-336)

Overall people living in the community compared to people residing in institutions use more community places, engage in more social activities, experience more personal integration, have more family contacts, make more of their own choices, and see improved adaptive behavior.

Research overwhelmingly demonstrates that people living in the community have fuller, more socially interactive, productive, and independent lives than people living in institutions.³ Moreover, these individuals have more opportunities to exercise choice in the community than do people in institutions.¹ They can decide on what types of meals they eat, where they work, when they sleep, where and if they attend church, and with whom they enter into relationships.

Research further demonstrates that people moving from institutions to the community have been extremely successful and that outcomes for people in the community are better than for individuals who remain segregated in institutions,³ including people who require substantial supports.⁴ Studies demonstrate that people who move from institutions to community settings have experiences that help them to improve their adaptive behavior skills,⁵ such as personal hygiene and food preparation.⁵ In fact, from the large body of research evidence now available, researchers make this statement:

“Deinstitutionalization of people with developmental disabilities in America has been one of the most successful and cost-effective social experiments.”⁶

Additionally, research shows that family members’ opinions change dramatically in favor of transition after the move has taken place. In one study, only 56% of families agreed with transition prior to their family member moving from the developmental center to the community. However, 82% agreed that the move to the community was a positive experience 3 months after it occurred.⁷

Community living for individuals with disabilities is cost effective but more importantly it allows for greater quality of life, fuller participation in society, larger social networks, positive behavioral outcomes and increased family satisfaction. In Louisiana, community living should be the guiding principle for services and supports for people with disabilities, and all public policy should facilitate and support this outcome.

The Developmental Disabilities Council urgently recommends that Louisiana:

- 1) Provide adequate funding and build capacity for high quality individualized supports and services in the community for all people with developmental disabilities.
- 2) Continue to utilize Resource Allocation across all settings, including in small and large private and public ICFs-DD, to fairly distribute resources by allocating services according to need.
- 3) Halt admissions into state developmental centers and improve the use of alternative safety nets by
 - a) expanding the criteria for and the number of emergency waiver slots available,

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- b) implementing a comprehensive crisis prevention and intervention system for individuals in the community including:
- proactive preventive services, and
 - coordinated 24-hour crisis response services (including telephone hotline, mobile response teams, in-home crisis services, licensed short-term crisis residential services [private], and crisis response plans for hospitals and other general health care providers).
- 4) Develop and implement a plan to consolidate and close Louisiana's developmental centers.
- 5) Redirect resources in the developmental disability service system utilizing cost savings from Resource Allocation and the consolidation, closure, and sale of developmental centers to support individuals on the waiver waiting list and those living in the community.
- 6) Fully implement the Money Follows the Person program approved by the Centers for Medicaid and Medicare Services (CMS) to allow individuals residing in private ICFs/DD the option to move into the home and community of their choice.

References:

- ¹ Neely-Barnes, S., Marcenko, M. Weber, L. (2008). *Does Choice Influence Quality of Life for People with Mild Intellectual Disabilities?* *Intellectual and Developmental Disabilities*, 1, 12 – 26.
- ² Roberson, J., et. al. (2001). *Social Networks of People with Mental Retardation in Residential Settings.* Mental Retardation. American Association on Mental Retardation.
- ³ Lerman, P., Apgar, D. H., Jordan, T., (2005). *Longitudinal Changes in Adaptive Behaviors of Movers and Stayers: Findings From a Controlled Research Design*, 43, 25 – 42.
- ⁴ Conroy, J., Spreat, S., Yuskas & Elks, M. (2003). The Hissom Closure Outcomes Study: A Report on Six Years of Movement to Supported Living. *Mental Retardation*. 41, 263-273.
- ⁵ Kozma, A., Mansell, J., Beadle-Brown, J., (2009). *Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review.* *American Journal on Intellectual and Developmental Disabilities*, 114, 193 – 222.
- ⁶ Conroy, J., Garrow G., Fullerton, A., Brown, M. & Vascile, F. (2003). *Initial Outcomes of Community Placement for the People Who Moved From Stockley Center.* Completed for the Delaware Division of Developmental Disabilities Services.
- ⁷ Apgar, D. H., Lerman, P., Cook, S. (1999). *Closing Old Doors – Opening New Ones: A Three Month Follow-up of Former Residents of the North Princeton Developmental Center.* Newark, NJ, Developmental Disabilities Planning Institute.